



**Presidential Commission**  
*for the Study of Bioethical Issues*

## **TRANSCRIPT**

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## **Member Discussion**

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## SESSION 2: MEMBER DISCUSSION

DR. GUTMANN: Actually, I was going to ask if, Christine, did you have a comment you wanted to make relevant because you could take a minute to -- yeah. Put your -- and then we'll get -- yeah.

DR. GRADY: I was going to make a point that actually Laura made at the end before she left and that was that, you know, in terms of creating safe space for students to have these kinds of discussions, we first have to care about helping the teachers being prepared and that that's not a trivial task --

DR. GUTMANN: Uh-huh.

DR. GRADY: -- because teacher preparation, as everybody knows, is very different across different places --

DR. GUTMANN: Uh-huh.

DR. GRADY: -- and they have a lot on their plates.

DR. GUTMANN: Yeah. Yeah.

DR. GRADY: That was the point I was going to make.

DR. GUTMANN: Okay. Great. So welcome back everybody. We'll spend the rest of the day deliberating as a Commission potential recommendations to the President. We'll discuss recommendations concerning deliberation in this session, and this afternoon, after our lunch break, we'll discuss recommendations on bioethics education, then potential recommendations focusing on the intersection of the two.

So now we'll start with deliberation and I'm going to outline without trying to wordsmith it. I don't think we have to worry about wordsmithing now. We want to talk about the big issues. I'll outline some -- the, you know, recommendations.

In our last two meetings that we deliberated, as well as our meeting in November

2014, we have heard from speakers on the value of democratic deliberation, deliberation in a democracy, its application to bioethics, and the importance of building deliberative skills and deliberative virtues, such as understanding and respect for competing points of view in young people to prepare them to participate as citizens in our democracy. And I just want to reference Anita and Nita's comments and question in the last session which highlights how basic deliberative skills and virtues are to education in that in any issue that is or seen as controversial, teachers need to create a space in which students can voice their views and be respected even as other students disagree with them.

So it really is very basic that what we're talking about in deliberation and what both -- what David mentioned, you know, and argued for himself is very basic in young people to prepare them to participate as citizens in our democracy.

We also as a Commission have practiced the principles and skills and we hope virtues as well of deliberation throughout our tenure. I began our last meeting with examples of the impact of some of our recommendations and those of other bioethics advisory bodies to highlight the value of deliberation in navigating morally complex and sometimes also morally controversial topics in public policy related to developments in healthcare, science, and technology.

At that meeting we concluded that deliberative processes and values which include, for example, the value of intellectual freedom and responsibility, which is not something that we can take for granted as a society, should be incorporated into policy decisions, especially those with challenging ethical dimensions and that these processes and values should be guided by the best available evidence of what works.

We also acknowledged that more research is needed to refine the methods of deliberation and inform our understanding of what does work best. We have some of

the conclusions of that research we were presented to by people like Diana Hess and others, so we're not saying that there isn't evidence of what works and what doesn't work, but we really could use refining we might consider. So three potential recommendations in this area I want to put out.

First, deliberative practices are an effective tool for facilitating well-informed public engagement with bioethics and fostering an environment of mutual respect coupled with free expression. Citizens, policymakers, and opinion leaders should use public deliberation to inform policy decisions in health, science, and technology that have ethical dimensions.

This Commission's deliberations -- and now I want to use an example so we don't leave this just abstract. This Commission's deliberations on medical countermeasure research with children, those deliberations are a vivid example of this process in practice. This is a very important issue. The well-being of children in our society is at stake. It's a very controversial issue because it entails testing children and vaccines.

We started by paying close attention to and respecting many different ideas and opinions about the way forward and through effective open deliberation, the give and take of arguments, we arrived at recommendations that were not only well received by numerous stakeholders, but also implemented by BARDA and CDC.

We've seen effective public deliberation work in the United Kingdom as another example, work done by the Nuffield Council to develop policy for emerging therapies for the prevention of mitochondrial disease. Well-designed deliberations using diverse deliberative groups can help us better -- get better reasoned and more legitimate answers to bioethical questions that our society can act upon by putting intelligence and insight, by probing intelligence and insight across a range of backgrounds, expertise, and

perspectives. And both of these examples, the Nuffield Council and our Commission, are examples of which where we didn't start out with an answer. We started out by a question in a very difficult area. We heard diverse perspectives. We reasoned and argued among ourselves and we came up -- in the case of the biomedical countermeasures, we came up with an answer that was ethically and scientifically defensible and it was a better answer than where we in the government began.

So that's number one recommendation.

Second, those involved in deliberative activities should use available empirical evidence about methods for deliberation and ensure that they are designed and conducted according to best practices. For example, participants in deliberation should give reasons for their arguments that are accessible and respectful of fellow deliberators. This is not meant to be -- this is meant to be minimally constraining rather than maximally constraining.

In other words, if you shout and name call, you're not going to get the kind of reasoned deliberation that is optimal and needed in a society.

In addition, for deliberation to be maximally useful and productive in moving a democracy forward, the issues chosen for deliberation should raise questions that have not yet been definitively answered. So you should deliberate about things in which you can be maximally productive and those things are things in which there are questions and they -- that haven't yet been answered.

Okay. Third, we could recommend that scholars and others who use deliberative approaches should continue to assess the most effective methods of deliberation as a tool for policymaking and public engagement in bioethics. This is signaling that there's more work to be done on figuring out what works best and we should try to figure that

out.

For deliberation to be more widely used and supported as a form of public and political engagement, we need a better understanding of how well different kinds of deliberation work and which kinds work best under different circumstances, taking into account legal, practical, human, and behavioral constraints and opportunities.

So I've summarized the content of three potential recommendations, but certainly not their exact language and I hope our discussion today and throughout the day will similarly focus on substance and I open it up for comments by Commission members.

And I'll begin with Dan and then Christine and we'll go from there.

DR. SULMASY: Three points -- thanks, Amy. The first point is that I would hope particularly in light of some of the discussion we had earlier today that in our run up to the first recommendation, that we sort of not sort of anchor things only within our own deliberations, but really sort of couch it within the larger question of the sort of good of deliberation as a public process in general to really --

DR. GUTMANN: Yeah. Oh, sorry.

DR. SULMASY: -- so start there first, then kind of give our own experience with it. I think that would be more robust and in keeping with the previous discussions.

DR. GUTMANN: So this is Dan's comment, which I think is very well taken is not -- is how to preface the recommendation --

DR. SULMASY: Correct. Correct.

DR. GUTMANN: -- and to make sure we preface the recommendation in how basic deliberation is --

DR. SULMASY: Uh-huh.

DR. GUTMANN: -- in a democracy and in intellectual life for getting bringing

evidence and principles together. Right?

DR. SULMASY: Right.

DR. GUTMANN: Good.

DR. SULMASY: Second point is a bit more substantive. I'm wondering about our use of the phrase "public deliberation" instead of "democratic deliberation." I think that public deliberation, unless and you tell me otherwise, is a sort of looser --

DR. GUTMANN: Yes.

DR. SULMASY: -- looser term, but I think that we have used principles that obviously you're very familiar with

DR. GUTMANN: Yeah. Right.

DR. SULMASY: -- of democratic deliberation, which have more substance or are more precise and have more to anchor them and I'm just wondering about whether we want to use the more general point versus saying that there is a term of art which describes a particular approach that has a philosophical justification, rationale, and a set of principles that aren't even included in our report.

DR. GUTMANN: Right.

DR. SULMASY: So it's just a question for -- for you perhaps and then for all of us if we want to think about which is the better term to use.

DR. GUTMANN: Yeah. So the term "democratic deliberation" is more precise and it's precise in the way that Nita's earlier comment totally supports, which is democratic deliberation is one that supports the kind of safe space for argument and reasoning among citizens in a democracy. It doesn't require that it always be, you know, and it can't always be deliberation among everybody, the many, but it always requires that the kind of deliberation, if it's going to be called democratic deliberation, is

consistent with mutual respect for diverse opinions across, you know, in order to get better and more legitimate outcomes. So we --

DR. WAGNER: What's the advantage -- excuse me. So is there any advantage to the public deliberation phrase, particularly if we would have to redefine something where democratic deliberation is well-defined in literature?

DR. GUTMANN: No. I think it's better to use democratic deliberation --

DR. WAGNER: I agree.

DR. GUTMANN: -- because it's not -- democratic deliberation isn't always in public. Our deliberation is, but there are -- you know, it would be a mistake to think democratic deliberation always should be in public. There are times when in order to create the space that people can argue without being vilified in a blog, you know, in a social media space, they need to discuss things in, you know, private and then -- but democratic deliberation does require that ultimately the outcomes be made public and subject to public discussion. That's part of democracy, but I think democratic deliberation is the more accurate term.

DR. WAGNER: Okay.

DR. GUTMANN: And Christine? Christine?

Are you -- did you have one other thing?

DR. SULMASY: It's minor. Maybe it's --

DR. GUTMANN: Okay. Okay. We'll come -- Christine.

Thanks, Dan.

DR. GRADY: So I just wanted to make sure that we have explicitly recognized, and maybe it's implicit in what you said about best practices --

DR. GUTMANN: Yeah.



DR. GRADY: -- but explicitly recognize that evidence and, you know, what some people call facts are very important and that some of the things that get in the way of good deliberation and some of the models that we see in public spaces are disagreement about the facts --

DR. GUTMANN: Uh-huh.

DR. GRADY: -- or spinning the facts in a different way. And we had at least one of our report where we talked about fact-checking. I mean, I think there is a -- part of this process requires and I just think that we need to be explicit about it --

DR. GUTMANN: Uh-huh.

DR. GRADY: -- requires careful gathering of the evidence and discussion about --

DR. GUTMANN: Okay.

DR. GRADY: -- what the facts are --

DR. GUTMANN: Let's make two points there on the one point. One is I think we ought to in this recommendation reiterate the importance of factcheck.org for things that are established, but may not be known.

The second point is there's -- we have to also deliberate about the facts. Not all facts are well-established and it's really important that scientists and people in, you know -- who aren't scientists be able to deliberate about what it takes to get to the facts and to understand that facts evolve over -- you know, the knowledge of facts evolve and science is essential to that and it's essential that we give science space for that.

DR. GRADY: Can I just add --

DR. GUTMANN: Please.

DR. GRADY: -- I mean, I think in the two examples that you gave, our report on

pediatric countermeasures -- experimenting on countermeasures and the UK HFEA process, you know, both of those relied on some set of -- we had to understand the information. We had to understand what the options were, what the data were, et cetera, in order to be able to say anything intelligible about those, and so --

DR. GUTMANN: Yeah.

DR. GRADY: -- I just want to make sure that we're clear in what we write, that that's a part of the process.

DR. GUTMANN: Yeah. I think our countermeasures deliberations might be an excellent example for getting the facts right because even those people who were not presenting the ethics of it, but presenting the facts, at first we had a Rashomon experience of getting different parts of the -- so the facts you needed to know about -- in order to get to a recommendation on how best -- morally best and scientifically best to test a vaccine on children, you had to know facts that we gathered in the process of deliberation and that the previous commission asked us -- said they didn't -- they weren't making a determination on the ethics and then HHS asked us to deliberate.

We had to get -- gather all the facts. They weren't just transparently available and I think our deliberative process in hearing from many people was part of gathering all the facts of the matter, as well as deliberating about the effects.

Nita?

DR. FARAHAANY: So thank you for laying those out. I think that they're important and I hope will contribute to the dialogue. No pun intended given that we're talking about democratic --

DR. GUTMANN: Yeah. No.

DR. FARAHAANY: -- deliberation. The one thing I think would be useful to add

is the structure. So --

DR. GUTMANN: Uh-huh.

DR. FARAHANY: -- you know, we point to a couple of examples, both of which had essentially executive level leadership guiding the process of democratic deliberation. So the HFEA process had a structure in place. They first did the scientific analysis through the HFEA, which was a yearlong process, looking and gathering it -- the scientific facts. Then the Nuffield Bioethics Council, which is an organized body, held public meetings and hearings and guided the process.

DR. GUTMANN: Uh-huh.

DR. FARAHANY: And the way that we've talking, I think, so far is great aspirationally, but not mechanically.

DR. GUTMANN: Okay.

DR. FARAHANY: And I think we really need something mechanically to talk about. So I think of course it's wonderful and we should be promoting this idea of democratic deliberation, but exactly how does it happen? If it's not the Bioethics Commission who's taking it up and saying here's an important issue on which we are going to provide the structure, the help, and the establishment of the facts and guide the process through, then who does it?

And one of the things that I really liked about some of our reports is our recommendations have been directed very specifically at particular individuals, bodies, et cetera, and right now, the way we've talked about it is just sort of a broad, "We should do this." And so in the absence of the Bioethics Commission and in the absence of clear funding, given that many bioethics issues might arise at a state level or at a local level, who is the convener and how does it happen?

DR. GUTMANN: Yeah.

DR. FARAHANY: And I think providing some models that are not just executive level leadership for models of convening would be good. Some of the processes that have followed on synthetic biology are nice examples where they've been a number of public forums and a number of conveners from non-governmental organizations, nonprofit organizations, educational institutions pointing to who could be the convener of public deliberation and exactly what that would look like, I think would be helpful.

DR. GUTMANN: Yeah.

DR. FARAHANY: And laying out the structure of what a process might look like. So it can happen in many different ways, but quite how does one get started? You have an issue. What are the preconditions for democratic deliberation? Well, one is you need time. It can't be a public emergency. It needs to be something in which there's time.

The second is you have to start with a set of facts, right, and so the best way to start the public dialogue is to establish what the facts are and to get the scientific facts out on the table. How do you get to those facts -- that you have an agreed upon set of facts? Once you get to the agreed upon set of facts, quite how broadly does the deliberation need to be and what does the guidelines of the deliberation need to be?

DR. GUTMANN: Yeah.

DR. FARAHANY: I think setting it up that mechanically almost, that prescriptively in some ways, but leaving lots of room for people to be innovative within that framework would make it a much more impactful recommendation or set of recommendations. So I like the aspirational quality. I want us to go further in --

DR. GUTMANN: Yeah.

DR. FARAHANY: -- providing some context on how to do it.

DR. GUTMANN: So let me and then Jim add to that.

So there are two parts of the mechanics, if you will, there's a structure in the process and I think it would be good to speak to the way -- what kinds of -- to give examples, I think. So New York State, for example, when the whole issue of surrogate parenting was really hot, New York State put together a task force that deliberated about it and issued guidelines that then were actually accepted. I think having -- showing that there are ways to structure and have this process, I think, is really important.

I just throw that out because, you know, Nita pointed to it's not always at the federal level. Something like surrogate parenting gets deliberate -- either it just gets done willy-nilly or left -- or there's a deliberative body.

I would say we should recommend that there be a bioethics -- you know, that bioethics commissions continue to be deliberative because we've really -- there are things that we deliberated on, it did have an effect because the way we deliberated.

Yeah. And Jim?

DR. SULMASY: Just --

DR. GUTMANN: We'll let Jim and then Dan. Okay. Okay.

DR. SULMASY: -- very quickly and point to that New York State has a standing bioethics --

DR. GUTMANN: There you go.

DR. SULMASY: -- task force and that might be something to think about too. They didn't just do it on that issue. So --

DR. GUTMANN: Right. Right. Although they did put this task force together

for that issue, but I agree that's a good -- Jim?

DR. WAGNER: I just wanted to support this notion --

DR. GUTMANN: Yeah.

DR. WAGNER: -- that it ought to be in the report with as much detail as possible. In fact, I've been struggling with how it is we want to -- and I think this gives us a mechanism, actually, to bridge between our recommendations on deliberation --

DR. GUTMANN: I think you have to --

DR. WAGNER: -- to -- it gives an opportunity --

DR. GUTMANN: Yeah.

DR. WAGNER: -- including it also gives us an opportunity to bridge between our recommendations on deliberation and those we'll discuss this afternoon on education. I wonder, though, if it wouldn't be well for us to recommend to the staff, actually, that this would be a great place to develop an educational module around how it is one does --

DR. GUTMANN: Yes.

DR. WAGNER: -- democratic deliberation and we --

DR. GUTMANN: And I think doing this, getting the materials and doing something on -- ultimately online would be terrific so it's available.

Raju?

DR. KUCHERLAPATI: You gave a couple of examples of how democratic deliberation has been very useful. Certainly this group is involved in democratic deliberation, other things like Nuffield Council that you talked about, and we have other examples of -- they were talking about, but I think it also would be important to provide possibly examples where democratic deliberation has not been used and as a result of

that, the conclusions that were reached --

DR. GUTMANN: Yep.

DR. KUCHERLAPATI: -- or recommendations that were made happened to be inappropriate.

DR. GUTMANN: Yep. Yeah. There are many examples of that and I think we should pick selectively -- I mean pick some representative examples. I think that's important and I think that's really important to do. Yeah.

DR. KUCHERLAPATI: Given that, I think that, you know, is it possible to provide recommendations to be able to say what practically needs to be done to ensure that there will be democratic deliberation --

DR. GUTMANN: Yeah.

DR. KUCHERLAPATI: -- on a particular issue.

DR. GUTMANN: Yep.

DR. KUCHERLAPATI: I mean, what is it that lacks, you know, in a --

DR. GUTMANN: Yeah.

DR. KUCHERLAPATI: -- particular group --

DR. GUTMANN: Yeah.

DR. KUCHERLAPATI: -- or what are the dynamics of the group that would not allow it? And we know many examples of that and say what can be positively be done to enhance democratic --

DR. GUTMANN: Yep. Yep.

DR. KUCHERLAPATI: -- deliberation?

DR. GUTMANN: Good. Good. Any other -- yes, Anita?

DR. ALLEN: This is a smaller point, but in describing the process of democratic

deliberation, Amy, you mentioned that mutual respect is very important and I think we should probably say a little bit more about what mutual respect entails. You know, one model is you're sitting around a conference table. Everybody takes turns, but, you know, a lot of people shout in a friendly way. A lot of people use sarcasm and other sorts of discourse, but it can also be constructive.

So I don't want us to leave the impression somehow democratic deliberation among ordinary people --

DR. GUTMANN: Yeah.

DR. ALLEN: -- needs to look like the UN.

DR. GUTMANN: Right.

DR. ALLEN: You know?

DR. GUTMANN: Right.

DR. ALLEN: Yeah.

DR. GUTMANN: Well, there is a lot of shouting in the UN actually, so that may not be the -- I think here it is the case that in democracy and disagreement, Dennis Thompson and I do talk about how democratic deliberation doesn't take the whole space up in democracy, that many groups, grassroots groups who, you know, form movements are -- that's part of democratic discourse, if you will, and deliberation needs to build on that, not push that out. I mean it's analogous to what I said about -- you know, testing can't be all of education.

Democratic deliberation, which people like and enjoy much more than testing, still isn't all of the discussion that goes on in a democracy and we can -- we could take it from -- you know, we have a discussion of mutual respect and it's not all warm and fuzzy. It's arguing, but just also listening and not dismissing points of view just because



they're different from one and I think your point, which is democratic deliberation is consistent with having a space where people shout and demonstrate and get attention because they otherwise wouldn't.

I do think that the civil rights movement and Martin Luther King's example is a good example of how you can have both grassroots movements and also deliberation on important issues.

Dan?

DR. SULMASY: On your -- the second recommendation, we're talking now about mutual respect, you talked about the sort of minimum criteria being giving reasons and having respect for fellow participants in the process and I know those are two -- that you're picking out from a wider range of conditions, but I'm wondering again in terms of the discussion we had earlier whether we shouldn't mention for the minimum processes inclusivity and engaging a wide range of stakeholders and beliefs being part of the sort of --

DR. GUTMANN: Yes, I think that is important. I think that's why we're deliberating here. Again, this is like --

DR. SULMASY: Right. Right. We're deliberating about deliberation.

DR. GUTMANN: Right, to be accessible and --

DR. SULMASY: Yeah. Yeah.

DR. GUTMANN: -- and respectful --

DR. SULMASY: Yeah.

DR. GUTMANN: -- of fellow deliberators and that one deliberates in an inclusive way.

DR. SULMASY: Right. Right.

DR. GUTMANN: And one doesn't start by being -- one starts by being inclusive and if some people don't want to be part of it, you can't force them --

DR. SULMASY: Right.

DR. GUTMANN: -- to be, but the more inclusive one is --

DR. SULMASY: Uh-huh. Uh-huh.

DR. GUTMANN: -- the better --

DR. SULMASY: Uh-huh.

DR. GUTMANN: -- as far as the legitimacy of the deliberations and the getting as much information, indeed often more facts --

DR. SULMASY: Uh-huh.

DR. GUTMANN: -- into the deliberation as well.

I -- we don't want to leave the impression -- I think it's really important -- this goes to Christine's point -- that you begin by having all the facts and then you argue about the values. I want to -- on these issues, it's not obvious at the beginning what all the facts are and being more inclusive --

DR. SULMASY: Uh-huh.

DR. GUTMANN: -- on the empirical as well as the evaluative side.

DR. SULMASY: And so it's iterative rather than --

DR. GUTMANN: Right, it's iterative.

And the other thing I would say is sometimes the principles are as important and consensus building as the facts are. So the principle of every individual should -- has a life to lead and we should do -- we should begin by doing no harm and see where that gets us. We should begin by -- with intellectual freedom and responsibility.

I mean, we began with certain principles and values which are built in to our

legal and constitutional system. We can argue about them just as we can argue about facts, but we should begin with the ones that are basic and fundamental to our society and see if we can establish -- we can get to answers about controversial issues by touching base with those values as well as with the facts.

I just think it's important not to think that all values are controversial. They become controversial when you try to apply them, but they're often very basic to how we see ourselves and live our lives.

Nita?

DR. FARAHANY: Agreed. I'll start there.

DR. GUTMANN: Yeah. Yeah.

DR. FARAHANY: And forgive me for drilling down into mechanics again, but I --

DR. GUTMANN: No.

DR. FARAHANY: -- want to go mechanics again. So --

DR. GUTMANN: We need to be more robust on the mechanics, so let's drill down.

DR. FARAHANY: Well, so I want to -- the inclusiveness point, right, we had a conversation in the last panel about safe space and trying to give some meaning as to what that means. Inclusiveness, I think, gets at that same issue again.

We are having a problem in this country at every level of democracy of creating a space for inclusive dialogue and so I think we need to brainstorm some how do we on these difficult topics where there are conflicts in values too, right? So we can start with some values that are quite basic, but, you know, if we go to issues like the mitochondrial issue, that the HFEA and Nuffield Bioethics Council were looking at,

these touch on issues of prolife and prochoice and divisions around what we should be doing with fetal tissue research and germ line editing and get to some conflicts of values.

And I think they managed to have a very constructive dialogue there, which is a wonderful model.

DR. GUTMANN: Yeah.

DR. FARAHAANY: Some people call it a unicorn in the world of bioethics, though, and so how do we have that not be a unicorn?

DR. GUTMANN: Yeah.

DR. FARAHAANY: How do we actually bring --

DR. GUTMANN: Yeah.

DR. FARAHAANY: -- all of the voices to the table and what are the mechanisms in democratic deliberation that could enable people to have this conversation, and I think tying into the education space, that -- and the recommendations on education, I think if we can start to define what a safe space may mean from the earliest levels of people not being told that they shouldn't speak or that they shouldn't bring their different values to the table, but taught how they can bring their different values to the table and different opinions and different perspectives and still have them treated as legitimate differences, even if their differences will not be the ones that are codified into policy --

DR. GUTMANN: Uh-huh.

DR. FARAHAANY: -- at the end of the day, they are heard and listened to.

DR. GUTMANN: Yeah.

DR. FARAHAANY: How do we do that? And so I think, you know -- I don't have the answer to that --

DR. GUTMANN: No.

DR. FARAHANY: -- and I'm hoping we can infuse some of that into this report to both talk about at the education level, how we create safe spaces for dialogue, and what a safe space would mean in this context. And second, how that safe space could carry forward into public dialogue that could be more inclusive as well.

So I put that out there to say how do we do it --

DR. GUTMANN: Yeah. Yeah. Yeah.

DR. WAGNER: But I like the notion of actually using safe space. That's an involving definition or devolving definition right now in deliberative engagement --

DR. FARAHANY: Right.

DR. WAGNER: -- and for us to claim it for this purpose --

DR. FARAHANY: Right.

DR. WAGNER: -- might also be something that stands to be referenced for use in other purposes --

DR. GUTMANN: Yeah.

DR. WAGNER: -- if we can capture --

DR. GUTMANN: Yeah.

DR. WAGNER: -- what the essence of it means to be safe for deliberative practice --

DR. GUTMANN: Yeah.

DR. WAGNER: -- for productive deliberative practice that would be a great contribution.

DR. FARAHANY: And for voicing not quelling differences.

DR. GUTMANN: Right. And there are -- I think we should use examples. I'll

go back to the New York State, the task force, because it's taken up really controversial issues and one might agree or disagree with its conclusions, but -- so it gives an example of Nita's point that people are heard. The whole point is people are heard even if -- and respected even if the conclusion isn't what they wish.

And there are -- it isn't -- you know, so the Nuffield Council isn't a unicorn, although now -- right now we're facing a public -- you know, public spaces in which it just -- it doesn't seem like people are listening very much and that's not -- that's true. I want to go back. That's true to facts as well as values. It's not as if people in the public space, if they're not deliberating and giving reasons and bringing science as well ethics to bear, agree on the facts or the values.

DR. WAGNER: That's true.

DR. GUTMANN: Yeah. Christine?

DR. GRADY: So I would love us to think about using some examples that are much, I don't know if smaller is the right word, but at a different level. So, for example, ethics committees, I think --

DR. GUTMANN: Uh-huh.

DR. GRADY: -- they use processes and methods that look a lot like --

DR. GUTMANN: Yep.

DR. GRADY: -- democratic deliberation and I think they should and so I think we could recognize that it's not just, you know, national or state level important decisions, but local institutional decisions that get made this way.

DR. GUTMANN: So --

DR. SULMASY: Particularly with respect to the policies that are developed for the institutions, I'm not sure I buy it all the way down to the bedside, but at least for -- at

least for policy, anyways.

DR. GUTMANN: So I would say that -- and, again, you could take it out of democracy and disagreement, that deliberation about how to best come to legitimate well-reasoned policies that then are publicly known is consistent with having what Christine said, ethics committees which do deliberate, but also bedside deliberations with patients and so on are -- you have to do them at the bedside and consistent with, you know, privacy and so on.

That isn't an example of democratic deliberation, but it is an example that's consistent with policies that are deliberated higher up. So the policy would be if you have decisions to make with a patient, you have to do them in private with understanding and dialogue.

DR. SULMASY: It comes down to a question of what it is that actually, you know, happens at the bedside. So I would agree that ethics committees, when they are setting policies for the hospital, including policies about ethics consultation --

DR. GUTMANN: Yeah.

DR. SULMASY: -- are engaging in a form of democratic deliberation --

DR. GUTMANN: Right.

DR. SULMASY: -- but deciding what's the right and the good healing act for this patient in these circumstances is an exercise in common sense reasoning, particular judgments about particular individuals, and I don't think is really democratic deliberation, per se, at the bedside.

DR. GUTMANN: No, but it is --

DR. SULMASY: Yeah. Yeah.

DR. GUTMANN: -- consistent with and what perspective would recommend as

opposed to -- you wouldn't recommend having that be deliberated in public. You would recommend it being reasoned in private. So I think we should --

DR. SULMASY: There are now --

DR. GUTMANN: No, Dan, I'm just trying to say that we don't want to suggest that democratic deliberation requires public, open, inclusive deliberation about issues of the -- that should be patient, you know, doctor issues. I mean, there's a space for that --

DR. SULMASY: Yeah.

DR. GUTMANN: -- that is recommended by this perspective rather than -- it doesn't always recommend open, inclusive deliberation.

DR. WAGNER: Uh-huh. This question does get to the --

DR. GUTMANN: I think it's just important that we're not saying you have to deliberate democratically and inclusively about issues about your own well-being with a doctor.

DR. WAGNER: You shouldn't take autonomy away, is what you're saying.

DR. GUTMANN: Yeah.

DR. WAGNER: Yeah.

DR. GRADY: But it's still important to recognize that ethics committees do more than that. So that's --

DR. GUTMANN: Well --

DR. GRADY: -- some of the things they do are things that should be done using these methods.

DR. GUTMANN: Correct, but can you say more about -- I mean, just for the public record, I think that's important that we have -- we say something about deliberation that's at a more grass, you know, roots --



DR. GRADY: So a lot of them are policies. I guess I'm resistant to saying they're only policies, but --

DR. GUTMANN: Uh-huh.

DR. GRADY: -- certainly things that affect the organization or the way the ethics committee does its business when it's working with individuals or individual patients or clinicians, and then, you know, there are research ethics consultation services.

DR. GUTMANN: Yeah.

DR. GRADY: I mean, there are lots of ways that the process and the methods and the best practices that are true to democratic deliberation are appropriate for some of those activities that ethics committees do.

DR. SULMASY: Again, at the level of policy, so something like, you know, what the particular policy is going to be for an institution regarding a donation after cardiac death, right, is going to be something that will be set as the policy for the institution or its group deliberation about how the place will function as a group or policies about how ethics consults will be conducted, but I don't think that, you know, what Ms. -- ultimately is done for Ms. Jones, you know, involves a democratic deliberation of the members of the ethics committee. So that's the only distinction I want to make.

DR. GUTMANN: Right. Right.

DR. SULMASY: Yeah.

DR. GUTMANN: It's structured. So go back to Nita. There's a structure and a process which leaves room for non-deliberative decision making that you are referencing.

DR. WAGNER: Ask a question. In agreeing, Dan, with your target for this, that it's at the level of policy, does this define who it is and should we say up front in this report who it is we're addressing? I mean, we always deliver to the White House, but are we addressing it to regulatory agencies, policymakers, and commending it at other levels? I mean, shouldn't we open with something like that to help us clarify our purpose?

DR. SULMASY: Yeah, I think this is the widest sort of audience we've had the most sort of bully pulpit kind of report we're doing and I think this is not just to the government and it makes it --

DR. GUTMANN: Right.

DR. SULMASY: -- a little more difficult for you, Nita, in wanting to have the sort of concrete recommendations because we're not sort of saying X agency should do Y, but I think you're right to call us to be more specific about what we're recommending and maybe more a little bit -- a little bit more explicit about to whom we're speaking.

DR. GUTMANN: Yes, please.

DR. FARAHANY: So I agree. I mean I'm -- I don't mean that we should be saying, you know, the OSTP should be the body for democratic deliberation from here on out. What I mean is there's got to be a balance between an aspirational bully -- you know, sitting at the pulpit and giving our hope and aspirations about what this all would like and then making it possible to do so.

So we've included democratic deliberation in each of our reports. In a number of my bioethics classes, I have done as a case study encouraging to design a process of democratic deliberation.

DR. GUTMANN: Oh, yeah. That's great.

DR. FARAHANY: And they'll each take a different case and try to figure out what that is and they struggle mightily with it despite having, you know, kind of open resources and access to figure it out because I think the translation of it from the aspirational goals to what it looks like on the ground can be very challenging. I mean local levels. I mean nongovernment organizations. I mean the state task force. I mean the executive branch, but I mean --

DR. GUTMANN: Yeah. Yeah.

DR. FARAHANY: -- directing it to, you know, quite who is it in the sense of is it somebody who is passing a policy? Is it somebody who has an important decision to make? You know, who and when should one be engaged in the process of democratic deliberation? When is it best suited for?

And when you have that kind of idea of which situations are best suited to the process of democratic deliberation, and so I give the counterexample of a public health emergency is rarely the time that you can actually engage in a sustained democratic deliberation, so before then is when it needs to happen.

DR. GUTMANN: Right.

DR. FARAHANY: So when does it need to happen, under what circumstances, for what kinds of topics, and then how do you do it? And so by that, it's -- you know, so you need somebody who is the convener, right, and it may be somebodies who are conveners, but you need somebody who is the convener. You need to establish a set of facts and it needs to be an iterative process. You need time and forums in order to do so. You need a diverse set of stakeholders who are actually at the table having the conversation.

You need to create a safe space for the process of dialogue and conversation.

That kind of thing so that it's almost -- not so prescriptive because, of course, there are many ways in which you can democratic deliberation, but something more prescriptive than what we're doing right now --

DR. GUTMANN: Yeah.

DR. FARAHANY: -- to enable my students and other people who are actually wanting to design what a process of democratic deliberation would look like, how to do it, and then we have to answer some of the tricky questions like how do you fund it and, you know, who supports it and how is it supported because aspirations are great. Mechanics enable it to actually get translated from aspirations into real practice.

DR. GUTMANN: So there are two -- let me divide what you said into two parts. One is a kind of -- and I like it -- a checklist of what are the elements of a deliberative process and just as we found that surgeons do better when they -- which they resisted mightily, but they do a lot better in outcomes of surgery when they have a checklist. We could have a checklist of what are the elements of democratic deliberative processes and you gave some of the elements.

The second part is whether we're recommending a whole series of new structures or whether -- and/or I would -- let's put that aside for a moment. Are we recommending that existing bodies, including, you know, when there are bioethics commissions, ethics committees, professional associations who have policy questions, they become more deliberative and I would think for sure we're recommending that and a checklist would be great and it's not clear.

I think we don't have probably the time to figure out how many new things need to be created, but it doesn't take a -- and often it doesn't take a bigger budget to become more deliberative or if it is, it's marginal, to become more deliberative if you have an

existing body, and I think we should recommend because we've seen -- and this goes to Raju's question -- we've seen existing bodies that haven't deliberated and their outcomes are illegitimate. They're immediately called into question because they discuss things among a very narrow group. They came to a conclusion that wasn't respectful, didn't actually hear from competing views, and the government couldn't move forward with them because it had zero legitimacy.

So the -- both the intellectual value of deliberation and the political public legitimacy of it recommends it for existing bodies and I think we should make that recommendation with a nice checklist which may not have everything on it, but we could invite people to put other things on it.

Other questions and comments? Yes, Steve.

DR. HAUSER: So I very much like Nita's comments and would ask if more specificity about how to broadly engage people who are not engaged or not interested in a broader sense is an important objective rather than having vehicles for those who are already interested or engaged and we've commented at several of our past reports, maybe Ebola was a recent --

DR. GUTMANN: Uh-huh.

DR. HAUSER: -- great one about --

DR. GUTMANN: Yeah.

DR. HAUSER: -- natural opportunities that maybe we haven't maximally utilized for this purpose. There may be one next month on sports related traumatic brain injury --

DR. GUTMANN: Uh-huh.

DR. HAUSER: -- but these come periodically.

DR. GUTMANN: Yeah. Yeah. And the fact that once you have an emergency it's too late to have deliberation, you have to know what to do and what to communicate. We could reference our Ebola report on what we need to do now in deliberating about how best to react when an emergency happens.

I mean just a very basic example with Jim Wagner was at the site of -- Emory had a place to go for people who had manifest symptoms of Ebola and be treated. Well, there's no way you could create in an emergency situation that if it didn't exist and that's just -- and then how you treat people and how you treat caregivers and why the least restrictive means of containing is so important if we're going to react in a humane way in a case of a public health emergency. I think that's just a good example.

I think we really need to give basic examples of how you prepare ahead of time in a deliberative way.

Christine?

DR. GRADY: Actually, I have a question about that because I mean I agree with what you just said, and yet, I'm aware of examples in Liberia, for example, where they were in the midst of the emergency, but what they did was they took the time to have town meetings and really in-depth discussions about certain things --

DR. GUTMANN: Right.

DR. GRADY: -- before they decided to do them. Now, I don't know if that's an example of where the principles of democratic deliberation applied in that setting probably --

DR. GUTMANN: Yes.

DR. GRADY: -- better than in another --

DR. GUTMANN: I think that's right and they had to because in order --

DR. GRADY: They had to.

DR. GUTMANN: -- to move forward because they had to get community buy-in and they did use the principles of deliberation to do that and they were the only way of doing it. So even -- that's a good example of even in an emergency. If you haven't deliberated before and you don't have community cooperation where you need it, you have to do it.

DR. WAGNER: And that's also --

DR. GUTMANN: Yeah.

DR. WAGNER: -- that's also an example, Christine, of the --

DR. GUTMANN: And Nelson would be -- has been involved in that on the HIV front.

DR. WAGNER: Yeah. And that would be an example of your earlier point because those were heavy on facts, trying to discern and communicate what was known --

DR. GRADY: And what wasn't known.

DR. WAGNER: -- and what wasn't known, but in Sierra Leone, the way that the deceased should be handled and managed was as much about changing community practice and personal practice based on fact --

DR. GUTMANN: And that's because the --

DR. WAGNER: -- than it was debating whether or not and should be.

DR. GUTMANN: Right.

DR. WAGNER: Yeah.

DR. GUTMANN: And I think that's -- I hope in our report we can make this clear. That's a case where the controversy was about the facts. Everybody agreed that

they wanted to save lives. I mean, it wasn't -- and that's the value of --

DR. WAGNER: Exactly.

DR. GUTMANN: -- saving the most lives. There was no debate about saving lives. The debate was what are the facts and how do you do it and how does that affect the sacred practice of burying the dead, for example? That -- and that -- the public deliberation about that, Christine's absolutely right, in an emergency situation could not be sidelined because otherwise there would be no ability to, you know, move in the safest possible way forward.

DR. GRADY: And then there were also debates about --

DR. GUTMANN: But that's not ideal --

DR. GRADY: No, of course.

DR. GUTMANN: -- I mean, and I think what we have to push -- we have to really push is in the absence of an emergency, it's easy not to bring the public in and we are advocating in nonemergency, as well as when necessary --

DR. GRADY: Right.

DR. GUTMANN: -- in emergency situations finding -- using established structures to bring more of the public in.

Dan?

DR. SULMASY: This goes back to my very first intervention, something that I said was maybe more wordsmithing, but maybe really isn't and it's sort of being careful to look to the scope of the modifiers that we use in terms of our discussions. At points I've heard that we want to inform health, science, and technology ethics and policy decisions through this, but I think really we want to inform policy decisions that raise ethical issues in health, science, and technology, and I think that that -- if we can get the



distinction, that's really I think important.

Maybe I'll sort of tell the staff that, but do you sort of understand that it's sort of not just sort of all technology and health decisions because some of them can be really quite technical, but the scope of what we're doing is raising -- is using democratic deliberation to inform policy discussions regard -- that raise or regard ethical issues in health, science, and technology? And I think if we're -- we've got to be consistent about what our mission is and the scope of that.

DR. GUTMANN: Yeah.

DR. SULMASY: So that's just --

DR. GUTMANN: I think that's --

DR. SULMASY: -- yeah.

DR. GUTMANN: -- that's right.

DR. SULMASY: Is it valuable? You know, okay.

DR. GUTMANN. Yeah. I think that's right.

Anything else where -- good. This is terrific and we will adjourn for lunch.

Thank you, Commission members, very much.

We'll adjourn for lunch and we'll reconvene at 1:15. Is that correct? We'll reconvene at 1:15. Thank you all.

(Whereupon, at 11:45 a.m., a luncheon recess was taken.)